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Research paper

New priorities for disability research in Europe: Towards a user-led agenda☆

Nouvelles priorités de recherche sur le handicap en Europe : vers un programme dirigé par l'usager

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ABSTRACT

This paper presents findings from participatory action research with disabled people's organisations in European countries. The project 'European Research Agendas for Disability Equality' (EuRADE) sought to engage civil society organisations as agents of change in influencing future priorities for European disability research. The paper examines findings from a consultation with 68 organisations in 25 countries and illustrates how the research priorities identified by representative organisations of disabled people were used to impact on European-level research funding. The findings demonstrate the potential for mainstreaming and targeting disability issues in research that will have an impact on the lives of Europe's 65 million disabled people, using social model

☆ The paper was developed collaboratively. The views expressed are those of authors and research respondents and do not necessarily represent those of the European Disability Forum.

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and rights-based approaches. They also demonstrate how effective partnership between academia and activism adds to the social relevance and impact of research practice.

R É S U M É

Cet article présente les résultats d'une recherche participative menée avec des organisations de personnes handicapées de divers pays européens. Le projet European Research Agendas for Disability Equality (EuRADE) visait à impliquer les organisations de la société civile parce qu'elles sont des moteurs de changement pour influencer les futures priorités de la recherche européenne sur le handicap. L'article examine les résultats d'une étude menée auprès de 68 organisations dans 25 pays. Cet article montre comment les priorités de recherche identifiées par les organisations représentatives de personnes handicapées ont eu un impact sur le financement de la recherche au niveau européen. Les résultats démontrent que la reconnaissance du handicap comme problématique de droit de l'homme dans le domaine de la recherche a un impact direct sur la vie de 65 millions de personnes handicapées en Europe. Ces résultats démontrent également qu'un partenariat efficace entre les universités et les ONG améliore l'utilité sociale et l'impact de la recherche dans la société.

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European 'science in society' initiatives have sought to bring scientific knowledge closer to society (e.g. through public education and communication) but there has been less emphasis on bringing 'society' into the scientific process (i.e. as active partners in research rather than the recipients of scientific knowledge). However, within critical disability research, there has been a long-standing movement towards greater civil engagement in the research process (Barnes and Mercer, 1997; Goodley and Moore, 2000; Rioux and Bach, 1994; Shakespeare, 1996). This paper outlines a new agenda for European research on disability issues, an agenda led by organisations representing disabled people in European countries.

The act of researching disability became increasingly problematised as disabled people began to examine their relationship with researchers. For example, from his own experiences of being researched, Hunt (1981) argued that this relationship was essentially 'parasitic'. Abberley (1987: 5) argued that the sociology of disability remained 'theoretically backward' because it reproduced deficiencies like those found in 'racist and sexist sociology'. The treatment of disabled people as 'passive research subjects' (in both quantitative and qualitative studies) began to raise similar challenges to those previously posed by feminist researchers (such as Oakley, 1981; Stanley and Wise, 1983; Smith, 1988). Thus, for Oliver (1992: 102), the objectification of disabled people by social researchers suggested the reproduction of disabling social relations within the research process itself.

The methodological response to these developments, which will be familiar to students of critical disability studies, has been widely described as an 'emancipatory' research paradigm, sharing much in common with historic claims on research from feminist, anti-racist and anti-imperialist movements. The key features of such claims include a redefinition of the social relations of research production, a rejection of positivist and interpretative claims to 'objectivity' and demands for a committed political position from researchers. Reviewing the arguments presented by advocates of this paradigm, and their links with other anti-oppressive research claims, Stone and Priestley (1996) identified a number of core principles and challenges in doing emancipatory disability research. These included 'the surrender of falsely-premised claims to objectivity through overt political commitment to the struggles

of disabled people for self-emancipation', and the ontological grounding of research in social models of disability.

Such approaches also draw on a long tradition of critical engagement between social researchers and political actors in civil society. In particular, the historical emergence of new social movements posed challenges to traditions of positivism and objectivity in social science. Thus, Touraine (1985: 29) argued that it was difficult to understand social movements without identifying with them. Indeed, Touraine went so far as to propose that researchers seek to contribute to the radicalisation of social movements through a process of 'committed research' (*ibid:* 198). In seeking to operationalise this kind of commitment in the field of disability, researchers have increasingly sought to engage disabled people and their organisations in the implementation of their research projects. However, there has been less evidence of real engagement in shaping the research agenda itself. As Zarb (1992: 128) argued:

> Simply increasing participation and involvement will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how.

In this paper, we focus on the opportunities for European disability research within this framework. As the title suggests, the aim is to influence the agenda for research in Europe, re-framing it within the priorities of disabled people's organisations (DPOs). The data and discussion arise from a collaborative European project, grounded in the principles of co-participation between DPOs and researchers (described later).

European research policy and disability

European research policy has increasingly focused on benefit and impact. Investments in 'science and technology' have been viewed as contributing to the aims of the Lisbon Strategy, supporting its ambitions to create, in Europe, 'the most competitive and dynamic knowledge-based economy in the world'. Investing in research is intended to help European companies become more competitive, to create more and better jobs in Europe, and to improve quality of life in European countries. If Europe's 65 million disabled people are not to be excluded from these ambitions then it is essential that their needs are adequately addressed in research. Disabled people are consumers, workers and citizens too.

The Communication *More research for Europe*, and subsequent Action Plan, identified Europe's research 'investment gap', envisioning growth in investment to 3% of GDP (Commission of the European Communities, 2002; 2003). The Action Plan also noted a need for more 'integration of innovation-oriented activities in research projects' (p. 15) to enhance the take-up of new knowledge. Further, the European Commission (2005) advocated a 'common approach' with greater emphasis on user involvement in research. Whilst universities are urged to collaborate with 'industry', civil society involvement is equally important. As the Commission's innovation strategy highlights:

> . . .the innovation process involves not only the business sector, but also public authorities at national, regional and local level, civil society organisations, trade unions and consumers. . . Innovation depends on a strong demand from consumers and citizens for new and innovative products and services. . . It is fundamental that researchers and industry work closely together and maximise the social and economic benefits of new ideas. (Commission of the European Communities, 2006: 3)

For this reason, researchers should also respond to disabled people's 'demands' for knowledge to create environments, products and services facilitating rights to full participation and equality. This requires two parallel actions. First, we need a greater awareness amongst researchers and research funders about the knowledge needs and priorities of disabled consumers. Second, we need to ensure that disabled people can participate effectively in the process of research and innovation.

The latter actions have been extensively discussed in the disability studies literature, as outlined earlier, while the international disabled people's movement has strongly advocated the principle of 'nothing about us without us' (Driedger, 1989; Charlton, 1998) – a principle that applies also to

research. At the same time, the 'science in society' agenda has achieved a higher profile in European research funding (e.g. with €359 m dedicated to engaging social actors in the Capacities budget of the Seventh Framework research programme). Writing about industrial collaboration in biological science, Gibbons (1999: 11) concluded that 'A new contract must now ensure that scientific knowledge is "socially robust", and that its production is seen by society to be both transparent and participative'. Critical disability researchers, with their claims to emancipatory methodologies, should be well placed to respond to this challenge.

A key challenge is to ensure that social model and rights-based approaches are mainstreamed in research programmes that impact on disabled people's lives. In a submission to the Commission's Directorate of Research, the European Disability Forum (EDF) argued that: 'It is very important for disability issues to be separated from health issues and for research in these areas to be similarly distinguished and separated' (EDF, 2002). Some progress has been made, but there is much to do. Disability was not explicit in the main themes of the Sixth Framework Programme (FP6) but was addressed in a separate strand on Scientific Support to Policy (area 2.4 'Quality of life issues relating to handicapped/disabled people'). Some significant targeted studies have also been funded directly by the European Commission, outside the remit of the Framework Programme. The funding, in 2008, of a new policy-focused Academic Network of European Disability experts (ANED) is also encouraging.

The current Seventh Framework Programme (FP7) covers the period 2007–2013 and provides more than €50 billion for scientific co-operation, new ideas, support for individual researchers, and building scientific capacity. Approximately two thirds of this investment is in co-operative research projects, organised in 10 thematic areas, each with its own priorities and work programmes. These include: Health; Food, agriculture and fisheries, and biotechnology; Information and communication technologies; Nanosciences, nanotechnologies, materials and new production technologies; Energy; Environment; Transport; Socio-economic sciences and the humanities; Space; and Security.

During the first two years of FP7, some funds were awarded to projects concerning impairment, disability or accessibility. Within the 2007 Health programme, there were projects dealing with impairment prevention, health outcome measurement, and injury statistics (adopting a medical approach to the problematic of disability). However, the same programme also funded projects on access to healthcare for 'vulnerable people' and an assessment of older people's long-term care needs. The ICT programme included research on multisensory interfaces, 'smart homes', and assistive robots. There was targeted funding on 'Accessible and inclusive ICT', supporting projects on software accessibility simulation, accessibility frameworks, stakeholder dialogue, brain-computer interaction, and gaming technologies for 'marginalised youth'.

Considerations of accessibility were included in a programme on Sustainable Surface Transport (SST) and there was a call for projects on 'New mobility concepts for passengers ensuring accessibility for all'. This included funding for research on public transport accessibility, city mobility schemes, and concept work on 'intelligent' personal vehicles. Funding for the Science in Society programme included the project on which this paper is based and reference to web accessibility in a project on young people's use of science websites. A small number of researchers were funded by personal fellowships, reintegration grants or European Research Council grants to work on, for example, multisensory architectural design, social insurance schemes, personal interaction or tele-care.

The above examples hint at the scope for a greater inclusion of research supporting the full participation of disabled people in European society. What is less clear is the extent to which existing funding opportunities reflect the knowledge needs of disabled people themselves. This is our main concern in this paper. In the European context, FP7 provides a key opportunity for strategic agenda setting, an opportunity for a collaborative response from activist and academic communities. In a previous paper (Priestley et al., 2010), we examined the barriers to involving DPOs in the research process, drawing on the experiences of DPOs in European countries. In this paper, we turn to the research priorities of those organisations, and their potential to influence the European funding agenda.

Methods

The findings presented here arise from a collaborative project involving the European Disability Forum (EDF), the University of Leeds and Maastricht University. The project was funded by the

'Science in Society' strand of FP7 to build the research capacity of DPOs. The methods included consultation, capacity building and advocacy. EDF is the umbrella organisation of national and European organisations of disabled people and their families. It includes one national council of disabled people from each EU and EEA Member State plus a range of organisations representing different disability groups and campaign interests in Europe. The consultation was targeted to these organisations, particularly European-level organisations controlled by disabled people and sought to identify the research priorities of DPOs.

The partners discussed EDF's own priorities and reviewed its key policy papers from the previous five years. We also reviewed documents from Disabled People International, the European Community Disability Action Plan, the Council of Europe Disability Action Plan, and the United Nations Convention on the Rights of Persons with Disabilities. Key issues were identified and divided into thematic summaries, each reviewed by a research academic in the field. From this review, a typology of 21 research areas was developed and this formed the basis for the survey questionnaire.

The questionnaire design sought information about each organisation, its experiences of research, and its interest in research participation (a copy is available on the project website at http://www.eurade.eu). This included both closed and open questions. For example, the design included a grid of the 21 research areas. Respondents were invited to choose up to five and to rank their importance to disabled people in the next five years. They were also invited to expand, qualitatively, on their priorities and ideas for research to meet their knowledge needs. The questionnaire was produced in English and French, in accessible web-based format and print. The consultation was launched at the EDF General Assembly (in Slovenia, May 2008). In June 2008, details of the survey were distributed in an EDF mailing to all of its member organisations (with options to complete in any of seven languages).

After consolidating duplicate entries and removing two ineligible responses, valid responses were recorded from 68 civil society organisations in 25 countries. These included organisations based in 21 EU Member States, one candidate state (Croatia), two EFTA states (Iceland and Norway), and Serbia. There was no response from six EU countries (Austria, Cyprus, Estonia, Poland, Slovenia and Sweden) or from Turkey. DPOs from 23 countries were represented.

On the basis of the responses, and knowledge of the organisations, around three quarters of responses were from organisations controlled by disabled people or in which they were influential at a high level. Around two thirds had a significant level of control, with others had shared control between disabled people and other groups. Eight or nine responses were from organisations in which disabled people or their close advocates did not exercise significant control. Overall, 34 responses represented the target group of national or European level organisations controlled by disabled people.

The responses were analysed by the academic partners to produce a summary findings report. This was then validated (with additional analysis) by EDF, resulting in a collaborative report published on the project website and presented at a briefing event with key stakeholders hosted by the European Parliament in January 2009. This included representatives from more than 30 DPOs, members of the European Parliament and representatives of the European Commission (including those responsible for the FP7 Science in Society agenda).

The second phase involved capacity building with selected participants, who were supported to develop their ideas for future research. This included: a residential summer school on disability research methods, involving organisations and researchers from 13 countries; sponsorship of 12 DPO representatives to attend academic research conferences as critical observers; and, research training/mentoring for seven participants to develop specific proposals for research projects. These were presented at a second dissemination event in Brussels in June 2009, involving activists, academics and officers of the FP7 programmes.

On the basis of the research priorities identified in the questionnaire, a critical review was conducted, during summer 2009, of the FP7 work programmes for: Information and Communication Technologies, Social Sciences and Humanities; Transport, Health, and Science in Society. The aim was to identify existing funding opportunities for the research ideas identified by DPOs, for disability research more generally, and for DPO research involvement. EDF arranged lobbying meetings with relevant officers in the Commission responsible for specific research programmes, to communicate the priorities and to discuss the opportunities.

The evidence presented also builds on an accompanying paper, which reviews the challenges to achieving greater collaboration with DPOs in the research process (Priestley et al., 2010). The focus here is to identify the kinds of research areas identified as priorities by DPOs, to meet their knowledge needs, and to elaborate on the kinds of specific topics and projects that they proposed. Direct quotations used for illustration (those in *italics*) are drawn from qualitative responses to the questionnaire.

Findings: priorities for research

In the survey, the most frequently selected theme for research was 'education', with 36 votes, although only eight of these were first priority votes. The next most popular themes were 'mainstreaming disability in policies' and 'non-discrimination and human rights' (each with 32 votes) followed by 'employment', 'social exclusion and poverty' and 'support for independent living' (with 26 to 24 votes each). In terms of '1st priority' choices, 'non-discrimination and human rights' achieved the most votes followed by 'education' and 'access to health care'.

The three most popular choices for the DPOs were 'mainstreaming disability in policies', 'education' and 'non-discrimination and human rights'. Five other topics also received 10 or more votes (i.e. votes from a third or more of DPO respondents). They were employment; support for independent living; information and communication; social exclusion and poverty; and transport, mobility or tourism. It is relevant to note that only 10 out of the 21 topic areas received any '1st priority' vote from national or European level DPOs. It is these areas that we now examine in more detail.

Taking into account all of the responses, national and European DPOs provided a total of 115 ideas for possible research projects. This qualitative data was not always easy to interpret. For example, several organisations identified policy objectives or advocacy priorities but did not express them in terms of 'research' needs. However, others were adept at framing research questions and clearly articulated needs for specific kinds of knowledge or innovation. The following sub-sections summarize the key research priorities for national and European level DPOs.

Gender issues cut across the identified topics but some specific points were raised by respondents, who noted that '*women with disabilities face dual discrimination*' and that '*gender issues are majority issues for disability movement*'. Recognising gender inequalities is important if research is to acknowledge '*intersectional discrimination*'. In particular, there were calls for research to '*learn about employment and family opportunities*', and to consider *'pay discrimination*' affecting disabled women. Similarly, cross-cutting issues for disabled children and youth were prioritised by three respondents, noting a lack of reliable statistical data in European countries. As a consequence, gender and youth issues should be kept in mind throughout the following sections.

Mainstreaming disability in policies

This theme was both broad and topical (in terms of European policy making), which may explain the large number of votes. Many respondents referred to the problems of mainstreaming disability into general policies, and called for research that would facilitate this. For example:

> The local, national and European policy makers have difficulty to mainstream disability issues in all areas. . . . It is necessary to promote research in this area, such as appropriate statistics on discriminatory conditions, methodologies and services which can promote inclusion in education, employment, sport, etc.

Adopting a similar perspective, another wrote:

> Disability issues are not taken into account in the design of policies that address the general population. Evidence needed: (a) results from the monitoring of the existing social policies, (b) data on the percentage of people with disabilities that benefit from public services and goods.

The need for research to facilitate the involvement of DPOs was evident. For example:

> What tools can be developed to qualitatively and effectively improve the participation of disabled people's organisations in the reflection on and implementation of disability policies?
>
> . . .understanding and analysing the mechanisms for putting [mainstreaming] into place in some countries of the European Union should help us to be engaged in politics in a more effective way

There was the need for research to distinguish fields where mainstreaming was beneficial from those where a disability-specific approach was also appropriate. A number of respondents called for comparative research, to show how different countries/regions addressed mainstreaming. The key research needs identified by DPOs can be summarized as follows:

- evidence-based research on the impact of existing social policies and the relative effectiveness of disability-specific policies versus mainstream policies;
- research to understand, evaluate and improve the involvement of DPOs in policy making processes;
- analysis of the appropriateness and adequacy of different mainstreaming approaches, including sector specific research.

Education

Education emerged as a major concern, particularly because of the profound impact it has on social inclusion and employment. The poor quality education experienced by many disabled people, and a perceived lack of data about disabled school students in some European countries, was of concern. Research was seen as means to spread good practice, for example:

> Many countries have resistance to transforming the educational system in the direction of an inclusive system. Promoting research and spreading best practices can be very useful.

Several respondents made a strong case for new research, for example, arguing that research could identify '*new combinations of effective policies and examples of international practice*' (e.g. in identifying a '*way out from special schools*'). Such research could help to identify:

> What works? And what does not? And how are pupils and students included in the mainstream educational system with the needed support without creating social and attitudinal barriers, i.e. how is the development of strong and participating individuals supported while at the same time ensuring that special needs are catered for?
>
> What are the obstacles for better education of disabled people? How could they be overcome? What type of support would be needed to provide inclusive education for disabled people?

There were suggestions for research on good practice in learning processes and information technologies to support inclusion of pupils with specific impairments. For example:

> How do the educational institutes take hard of hearing students into consideration (educational inclusion)? Are all levels of education accessible for hard of hearing youth?

It is important to acknowledge the importance of 'Opportunities of lifelong learning for people with disabilities according their interest, needs and demand of labour market'. Therefore, it is also relevant to ask: 'What is the educational structure of disabled population?' The key research needs identified by DPOs can be summarized as follows:

- research based on best practices, on how to best integrate disabled people into the mainstream educational system without creating social and attitudinal barriers;
- research on the type of support that is needed, including teaching and learning processes/methods or information technologies adapted to specific impairments;
- research on levels of educational attainment amongst disabled people and the impact on their labour market participation;

- country-specific data about disabled children in schools (e.g. by impairment, sex and age);
- analysis of citizenship education in schools (e.g. teaching disability awareness);
- research on adult lifelong learning opportunities for disabled people (e.g. their interests and needs, the demands of the labour market, educational resources, processes and tools).

Non-discrimination and human rights

Like policy mainstreaming (discussed earlier), this was a broad and topical area, not least because of the challenges of the UN Convention. DPO research priorities revealed a need to understand disability discrimination and the way in which non-discrimination law operates, and for research on the implications of the Convention itself. For example:

> Evidence needed: (a) proof (statistical data, etc.) of all types of discriminatory behaviour (direct, indirect, etc.) in all areas of life, (b) proof of multiple discrimination, especially against the most vulnerable groups of disabled people like women with disabilities, immigrants with disabilities, etc.
>
> How do discrimination, obstacles and inequality manifest themselves in the lives of hard of hearing people? What different forms of discrimination are there? How to recognise institutional discrimination? And what kinds of institutional discrimination are there?
>
> Analyse why instruments such as reasonable accommodation have not worked as well as expected and the main barriers preventing its effective use. . . If strategic litigation is the way to go, how can this be most efficiently done? The success rate before courts has been low – how can this be improved?

The responses also revealed the need for comparative legal research in this area:

> A research on the type of policies being implemented by Member States would, in our opinion, highlight, or maybe not, the non-integration of a human-rights approach national policies.
>
> What is the existing legislation and its enforcement in comparison with other European countries?

The key research needs identified by DPOs can be summarized as follows:

- evidence-based research (e.g. statistical data) on types of discriminatory behaviour (direct, indirect, institutional, multiple discrimination) in all areas of life, including the most vulnerable groups (e.g. women, immigrants);
- research on how discrimination and inequality manifest for people with different types of impairment;
- research on how to empower disabled people to exercise the abstract principles of non-discrimination and human rights;
- examination of how disability non-discrimination law works in practice, including the barriers to effective enforcement (e.g. reasonable accommodation);
- investigation to find the determinants and impediments to successful litigation;
- research in support of new legislative frameworks to promote the principle of equality;
- comparative research on national legislation and policies, their enforcement and the extent to which they integrate a human rights approach in different European countries.

Employment

This is a more well-known area in European disability research but there was a perceived need for knowledge of the diverse experiences of people with different impairments. For example:

> We think that we need to focus more on invisible accessibility, such as cognitive problems at the workplace. Therefore more research is needed on how people with problems of e.g. memory,

attention, learning, etc. can benefit from special cognitive methods and information technology in order to handle a job.

What is the unemployment rate in the hard of hearing group? Are there any obstacles for hard of hearing people in transition from education to employment? Is the work environment accessible for hard of hearing people?

How can the labour market participation of people with visual impairment be increased? What mixture of measures work?

The key research needs identified by DPOs can be summarized as follows:

- research on accessibility and solutions for labour market participation (for all forms of impairment) including designed for all workplaces;
- comparative research on the employment situation of disabled people, including statistical data concerning people with different types of impairment, and on accommodation in the workplace;
- comparative analysis of the impact of existing employment legislation on disabled workers' rights and their maintenance in employment;
- research on the impact of unemployment on disabled people;
- research on disabled people as employers (e.g. of personal assistants).

Support for independent living vs. residential institutions

While the main focus was on understanding what works and best practice (e.g. in enabling living environments, direct payments, personal assistance, provision of enabling technologies), it was also seen as important to develop robust '*benchmarks that will allow for monitoring the numbers of people still living in institutions*'.

Independent living was viewed as a human right (asserted in the UN Convention). A key concern was to examine how such rights can be assured and supported for people with different impairments, of different ages, in different countries – in particular, '*the portability to be able to retain this [support] when moving around EU Member States*'. It would also be important to understand the '*costs and benefit for the whole society if IL will be provided*'. For example:

Research into how living environments in the best way contribute to the quality of life of persons with disabilities. How can it be organised to ensure the highest degree of own control over the life of the person with a disability according to different kinds of disabilities? In relation to this, experimentation with ways of basing living environments in the community is essential.

It would be beneficial to have information on how to develop supports for community living that will inform policy development and be accessible to service providers and disabled people's organisations. This research should include quality criteria, to ensure that services developed do support disabled people to live included in society.

More information on how the different models actually work for disabled people, do they deliver?

To provide more equitable provision of support for independent living, there is a need for new knowledge.

We do not know the composition of severely disabled persons who are not able to live an independent life. We do not know their circumstances and have no information whether they are able to live independent life under given conditions. With the above information, we could define the conditions, equipment necessary for them to live independent life.

The key research needs identified by DPOs can be summarized as follows:

- research on community-based living environments and how they can be organised to ensure the highest degree of choice and control in the lives of disabled people;
- research on the delivery of community-based services to inform policy development, service providers and DPOs (including quality criteria for inclusion in society);
- comparative research, based on best practices, on different models of support in different countries and on outcomes for disabled people (e.g. quality of life and personal achievements);
- research on the transferability of support systems for independent living between EU Member States;
- analysis of the costs and benefits, for the wider society, of support systems for independent living;
- research on the composition and living circumstances of severely disabled people to define necessary conditions and equipment provision to live an independent life;
- research to develop policies and practices of de-institutionalisation, taking into account the diverse needs of different groups of disabled people;
- research on the combined social challenges of ageing and disability.

Information and communication

A number of respondents called for innovation research on accessibility of electronic media and equipment. For example: '*inclusive accessibility of internet and information and communication systems, resources and products*', or the need for '*special devices for different people with different kinds of disabilities to use computers, telephones, etc.*', or '*data about the number of disabled people using new technologies and study on the cost of accessibility within the mass media*'. More broadly, respondents sought research into public perceptions of disability and how positive images could be communicated. For example:

> We would like to learn more about how we can eliminate psychological barriers, barriers in the minds of 'healthy population' and our policy makers. We also feel an absence of awareness and information about disability issues within the general public. That is why we are interested in what are the most effective ways for disseminating information and raising awareness. How to make people understand and accept the demands of people with disabilities?

Another respondent called for research on the portrayal of disabled people in mass media, and the perceptions of mass media managers. One proposal was for the '*elaboration of a European study on the correct portrayal of people with disabilities (and a guide also)*'.

The research needs identified by DPOs in this area were:

- research to develop information and communication systems, resources and products inclusive and accessible to disabled people;
- data about disabled people's use of ICT and new media technologies;
- research on the costs associated with accessibility within the mass media;
- research on the effectiveness of disability awareness raising and the communication of claims made by DPOs to policy makers and the general public;
- research on how disability is portrayed in the mass media and on the perceptions of public audiences, indentifying models for promoting equal opportunities.

Social exclusion and poverty

Addressing the widespread poverty and social disadvantage experienced by disabled people was an important issue. For example, respondents noted that, '*Disabled people still belong to the most poor and the most excluded inhabitants. We would like to find effective ways... to improve the situation*'. It is important to understand the current situation and its causes. Thus, '*Social exclusion and poverty often follow chronic illness and disabilities. It is important to make comparative studies of living conditions focusing on income, employment, quality of life, obstacles, social life, etc.*' More specifically:

> What are the costs of disability, what are the specifics of poverty and social exclusion for people with disabilities, what measures would help to decrease level of poverty of disabled people?

> Evidence needed: (a) proof (statistical data, etc.) of the low income of people with disabilities and their families, (b) data for the high financial needs that derive from disability condition, (c) study on the welfare system and its effectiveness, (d) research on the employment status of people with disabilities and the existing legislation that promotes it, (e) research on the educational, training and life long learning conditions that lead people with disabilities in low rate employment positions and jobs. Kind of research: (a) collection of statistical data, (b) review of the welfare, educational system, employment conditions and legislation.

Importantly, there is a need for '*research that will inform policy development*' and social action.

> Persons with disabilities are certainly disproportionately represented among the poor. However, specific data on the social situation of persons with disabilities does not exist, or is not publicly available. A comprehensive research on poverty among persons with disabilities should be undertaken urgently across Europe, in particular in low-income European countries. Thanks to this knowledge, NGOs would be able to act in a much more assertive way in order to reverse the trend towards an improved situation for persons with disabilities.

The key research needs identified by DPOs can be summarized as follows:

- comparative studies of disabled people's living conditions, focusing on income, employment, quality of life, obstacles, social life, education, training and life long learning, etc.;
- studies on European welfare systems and their effectiveness in satisfying the diverse needs of disabled people;
- analysis of the specifics of poverty and social exclusion for disabled people and identification of measures to address this (including data on the personal and household costs of living with impairment and disability);
- research on the relationship between educational exclusion, qualification, employment and poverty for disabled people;
- research to formulate effective welfare benefits systems tailored to individual needs;
- research to support the development and implementation of social and economic reintegration programmes and policies.

Accessibility in built environments and transport

The consultation responses included needs for research on accessible transport solutions, and technical specifications to facilitate orientation and mobility, including priorities for research on the built environment. Three responses called for research on environmental accessibility for people with visual impairments: for a '*comprehensive survey of all European tactile walking surface indicators and their application*'; research on '*public information material/stands which provide information in Braille*'; and on accessibility relating to electronic banking technologies.

The key research needs identified by DPOs can be summarized as follows:

- reviews of national, European and international legislation and technical standards promoting accessibility, evaluation of the extent to which they are put into practice, and identification of gaps in coverage;
- multidisciplinary research involving fields such as architecture, design, medicine, and ergonomics to achieve the incorporation of a disability perspective (both medical and social) into technical and industrial education;
- research on the accessibility of existing and future transport systems;
- research to promote accessibility and universal design in diverse product and system areas.

Organisations of disabled people

Echoing the spirit of the overall project, there was also demand for research about the capacities of DPOs themselves. Respondents were keen to understand the structure, funding, role and strategies of DPOs in different countries.

> What are the existing capacities of organisation of disabled people, what is the focus of their activities, who they are controlled by, how are they financed, how much do they influence policy? Recommendation on how to become better advocates for disabled people's rights.
>
> What should they look like? What is their role and what are their competencies in a modern society? How does a profile or a structure of an ideal organisation of persons with disabilities look?
>
> Is there a best way of obtaining influence for DPOs? Is obtaining power different when you are disabled?

The key research needs identified by DPOs can be summarized as follows:

- research on the organisational structures, roles, capacities, funding sources and sustainability of DPOs in different countries;
- research on the relationship and communication between service providers, disabled people and their organisations, its impact on planning and social inclusion;
- research on the extent to which DPOs influence policy, including evaluation of the most effective advocacy strategies for disabled people's rights.

Bioethics and rights to life

Human rights perspectives were not seen as well incorporated in this complex area, where interdisciplinary research, with a disability perspective, is needed. Research on how to challenge negative public perceptions of disability was again viewed as critical here, particularly given the potential impact on parents or prospective parents in life-or-death decisions. For example:

> The development of biomedicine (genetics, new technologies, euthanasia, etc.) is not aware about the human rights perspective and frequently discriminates against persons with disabilities. It is necessary to build a bioethics model of disability.
>
> How are pregnant mothers counselled, what information is given, what determines their decision? What information tools are doctors using to inform about disability? How are disabilities described in medical publications? A literature study of the image of disabilities in medical literature towards gynaecologists would be useful.

The priority areas for research included: a disability and human rights perspective in bioethics research; challenging cultural images of disabled people; providing appropriate information to prospective parents. The key research needs identified by DPOs can be summarized as follows:

- research that incorporates a disability and human rights perspective on bioethical technologies and debates, including the involvement of DPOs;
- analysis of the ways in which public and biomedical perceptions of impairment, and disability affect parents or prospective parents of disabled children (including tools used by doctors to inform and counsel prospective parents about disability);
- analysis of life-or-death decisions concerning disabled people and their impacts on professional and public perceptions;
- research on the representation of impairment and disability in medical literature intended for gynaecologists and other relevant practitioners;
- research on the ethical dimension of health care related to disability (e.g. organ transplant refusals, disregarding of 'informed consent' before administrating treatment, etc.)

Health care

It was clear that there are pressing issues of access to health care for disabled people, which must be considered as an issue of rights and barriers. 'User involvement' in health service provision was highlighted and there were calls to investigate the role of 'holistic' and 'complex' systems of health care and rehabilitation, including the social return of investing in such models. With massive investments and rapid changes in health technologies, there is also a need to consider the implications for disabled people. The key research needs identified by DPOs can be summarized as follows:

- research on inequalities in the type, appropriateness and quality of health care and treatment available to disabled people, including the consequences (e.g. loss of independence);
- research on policies and practices for user involvement in health care provision;
- analysis of holistic approaches to health care and rehabilitation;
- analysis of rapid change in medical technologies and their potential outcomes for disabled people.

Housing

With demands on support for independent living (highlighted earlier), there are challenges for housing research. Some respondents pointed to a lack of information on the housing situation of disabled people, which makes it difficult to plan appropriate support. Others highlighted the need for comparative research on housing options and support services in different European countries. For example:

> We do not know the composition of disabled persons from housing point of view. We have not information about the number of disabled persons living in family, alone, residential homes or institutions.
>
> We are very interested in the issues of the different housing options in relation to support services available. What are the different options available, the design issues (universal access, design for all. . .), the methods of financing. . . always with a view to comparing different European countries.

The key research needs identified by DPOs can be summarized as follows:

- improved statistical data on the housing situation of disabled people living in private households and residential institutions, including physical, geographic and tenure characteristics;
- research on the housing and community support needs of disabled people in rural and urban environments;
- comparative research on housing design and accessibility options, and methods of financing, available to disabled people in different European countries.

Sexuality, parenting and family life

Some specific priorities were raised in relation to parenting and family life (whilst recognising the gendered relations of this topic identified earlier). For example, it is important for research to investigate concerns where, '. . .*the right to be a mother and to have a family are questioned or refused*'. The importance of close personal relationships was highlighted in relation to sexuality and access to sexual relationships (including support to participate in such relationships). For example:

> We would be interested in learning more about all that helps or hinders the rights of disabled people to enjoy an emotional and sexual life like everybody else. What happens with persons who are not able to explore their sexuality on their own – the issue of sexual assistants?

The key research needs identified by DPOs can be summarized as follows:

- analysis of the barriers to parenthood for disabled women and men;
- research into the reasons for disabled people's longer-term dependency on their parents, and the support required to become more independent in an earlier phase of life;
- research on barriers to and experiences of living in close personal relationships;
- research into the barriers and types of support/assistance for disabled people's full enjoyment of rights to an emotional and sexual life on equal basis with others.

Opportunities for funding the research priorities

Following thematic analysis of the identified priorities, existing FP7 Work Programmes were reviewed. These programmes describe the broad areas in which the EC wishes to co-fund research. They contain the specific calls and conditions attached to funding (such as civil society involvement). Generally, the Work Programmes made few explicit references to disability. No references were found in Science in Society, Socio-economic Sciences and Humanities, or Health, whilst the Transport Work Programme made one isolated reference. The ICT Work Programme was most promising, containing a disability-specific call, and two further calls which explicitly recognised the needs of disabled people.

All of the Work Programmes fell far short of what might be expected in terms of mainstreaming disability (i.e. by making reference to disability in calls addressing general areas). For example, in the Transport Work Programme, calls related to customer satisfaction and safety, security, intermodality of transport and competitiveness made no reference to disability, failing to recognise the needs of disabled travellers, and the customer base they represent. Where calls sought global standards development (e.g. ICT), texts did not refer to design for all standards. In contrast, requirements relating to energy efficiency and sustainability were referred to explicitly. These failures are important, because researchers take their cue from the call texts, and are far more likely to include a disability dimension if they are encouraged to do so. Vague or ambiguous references to socio-economic needs, global standards or user communities are insufficient to stimulate attention on disability or accessibility.

A further characteristic of all Work Programmes was the limited scope for involvement of DPOs, although some possibilities existed for involving civil society organisations (CSOs) in Socio-economic Sciences and Humanities and in Transport. Thus, the FP7 Work Programmes demonstrated very little fit with the research priorities identified in the survey, and offered limited opportunities for the involvement of DPOs in research. Yet there is much scope within existing opportunities.

For example, there is some fit between concerns with health inequalities and user involvement and the Health Programme's focus on 'Improving the delivery of health care to European citizens'. The most likely opportunity here would be to seek the inclusion of disability as a cross-cutting issue in the broad health research topics in the 2011 call. There would also be potential to target health-related issues in research commissioned by the Commission's Directorates for Health and Consumer Affairs or Employment, Social Affairs and Equal Opportunities. With this in mind, the consultation priorities were discussed with representatives of the Health Research Directorate, which generated encouragement to participate in the debate to establish research topics (EDF were invited to make a presentation at the 2009 European Health Forum).

Within the Transport theme, there have been explicit opportunities (e.g. references to accessibility in the 2007–2008 Transport Work Programme) but no specific mention in the 2010 work programme. There has been a shift of emphasis in transport research priorities from safety towards energy efficiency. However, there may be opportunities to consider accessibility as a dimension of the sustainability agenda. EDF arranged meetings with representatives of the Surface Transport and Horizontal Aspects and Coordination Units (within the Commission's Research Directorate). This, in turn, led to consideration of ideas for lobbying with several European Technology Platforms (ETPs), which provide a framework for industry stakeholders to define research priorities. The findings were presented to the European Road Transport Research Advisory Council (ERTRAC), and the European Rail Research Advisory Council (ERRAC), as well as to the European Construction Technology Platform (ECTP), the eMobility platform (representing mobile technologies), and the Networked and Electronic Media platform (NEM). All platforms welcomed the integration of disability-related priorities in their strategic research agendas and several expressed an interest in the inclusion of 'design for all' process in research.

Likewise, there should be opportunity to include research on accessibility and 'design for all' within the Information and Communication Technologies Work Programme. Past projects have been funded with a specific call on 'Accessible and Assistive ICT' in 2009/2010 (and other references to 'rehabilitation' and 'chronic illness'). However, there remains a case for requiring some reference to accessibility in all future calls.

The Social Sciences and Humanities programme remains an under-exploited area of opportunity, in which disability has not been as effectively mainstreamed or targeted as gender or ethnicity. Many of the DPO proposals in key areas, like policy mainstreaming, support for independent living, human rights, or poverty and incomes would sit well in this context. However, discussion with Commission desk officers revealed that existing calls (such as 'Local welfare systems favouring social cohesion') require broad responses in which disability-specific projects would be unlikely to succeed. There is thus a case for disability-specific calls to be developed, and for the specification of disability elements (or work packages) within larger consortia projects addressing general themes. A significant indicator of progress was the inclusion of a new disability priority in the FP7 social sciences roadmap for 2011–2012 (although at the time of writing it is uncertain that this will be included in the 2011 work programme).

There is also scope for further capacity building involving DPOs in the Science in Society programme (which funded our project). Whilst disability may not be specifically identified, there are opportunities for projects that target the role of 'civil society organisations' (CSOs). More generally, within the major co-operative research programmes in all key areas, there are encouragements, often expectations, to involve 'small to medium-sized enterprises' (SMEs). Since some SME definitions have changed to include civil society organisations, it is essential to capitalise on these opportunities in forming project consortia.

Conclusions

The survey results provide evidence from a wide range of DPOs in European countries and provide the outline of a new European research agenda. However, the challenge is to ensure that these priorities influence the work of academic researchers. Whilst this may be partly achieved through dissemination of the priorities themselves, more needs to be done. The change that is required involves challenging both the form and content of research, including decision about who is to be involved in that research.

There is likely to be little disagreement about the broad thematic agenda, although some of the specific priorities may appear more urgent to DPOs than to researchers. It is of particular note that DPOs appear to prioritise types research that will provide a convincing evidence base for policy (not only more reliable statistical evidence but also more robust comparative evidence of 'good practice' and 'what works'). In this sense, the research agenda of European DPOs challenges academic disability studies to move beyond discursive analysis and to provide a stronger 'evidence-base' for political claims and policy decisions (but an evidence base that has been generated within social model or human rights paradigms of enquiry). In this sense, the research priorities of DPOs appear to have more in common with those of European policy makers in the disability field than with much of the academic research produced within disability studies.

There has been some resistance from the academic community to the 'evidence-based' policy trend, particularly where this has appeared to favour certain scientific methods over others. There is also an increasing pressure on universities to demonstrate the benefits of their research, particularly publicly-funded research in a period of economic restraint. Applicants for funding are increasingly required to demonstrate the relevance of their research, including 'impact plans' and the engagement of actors beyond the confines of academia. Whilst there has been some resistance to these cultural changes, we believe that critical disability studies has much to contribute in a climate of harsh competition for resources. Its exponents have the capacity and the desire to address issues of great social import and there is excellent potential to engage non-academic actors in the process.

To achieve this, however, it is also necessary to invest in the research capacity of DPOs – to build research collaborations in which they shape the agenda from the bottom-up. In many countries, DPOs struggle for sufficient resources to provide basic services. Their representatives are often volunteers,

unable to mobilise complex, competitive research funding applications. Very few current EU research programmes permit partner organisations to be funded at 100% of cost (with the exception of Coordination and Support Activities FP7, funding schemes are funded to a maximum 75% for public bodies, Higher Education Institutions and SMEs). In addition, only some DPOs can satisfy the SME criteria (there is no legal definition of NGOs), and their project-related overhead costs can only reach 60% of direct costs. Additional accessibility costs, such as accessible conference rooms and hotels, sign language interpretation, velotypists, Braille production raise the price of competitive research tenders.

Last, but not least, DPOs often lack the academic capacity to be involved in research projects as equal partners. The EuRADE project showed that funding their capacity building leads to concrete results: project participants were able to prepare strong project outlines and engage in discussions with prospective academic partners. However, such initiatives need to be extended. Further steps are needed to fund/organise regular DPOs capacity building, especially on technical research processes.

Tackling these challenges would place DPOs in a stronger position to influence the research that academics do. However, the academic community is also constrained, particularly by the availability of research funding. Therefore, we need to ensure that DPO priorities influence the key funding programmes at European level – that disability issues are both targeted and mainstreamed.

To summarize, the findings show that DPOs in Europe have clear priorities about the kinds of new knowledge and innovation that would be of public benefit. With appropriate investment in capacity building, they have the ability to articulate these needs as clear questions and proposals for new research. If the academic community is willing, and if participation barriers can be addressed, they are also ready to enter into partnerships with academic collaborators who can assist in realising those research ambitions. However, the European research funding environment constrains the opportunity structure for both parties. For this reason, concerted advocacy is required to convert identified priorities into real research opportunities.

The debate on 'emancipatory' and co-participatory disability research has focused for many years on micro-level collaborations in individual projects. Our experience shows that when DPOs and academics work together on these issues, much more can be achieved, and that there is a real possibility for disabled people to challenge the social relations of research production by shaping the agenda top-down, as well as bottom-up. If these battles can be won, and new funding opportunities emerge, then the academic community must also be ready to respond. We believe that the research agenda outlined in this paper offers this opportunity.

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